

Caregivers: A Vital Part of the Treatment Team

Webcast

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INTRODUCTION

Andrew:

Hello once again. This is Andrew Schorr with another one of our Patient Power programs on mdanderson.org. We do this every two weeks.

And anyone who's been touched by cancer, unless you're totally alone in the world, and I hope you're not, you know there's someone else trying to be by your side. There are people who care about you. Maybe it's a spouse. Maybe it's a very close friend, a partner, a sibling, but there is usually a caregiver. And there are actually millions of people across the country when you look at all illnesses who do this, many of them 20 hours a week, and they account for billions of dollars in unpaid services.

But it can take a toll. It's hard to be a caregiver, and often at M.D. Anderson people come from a distance to go to the number one cancer center. They come from near and often far, and then often the treatments go over time. So we're going to talk about are the services, what are the special needs of caregivers. We're calling our program "Caregivers: A Vital Part of the Treatment Team." And then our discussion today is how vital they are but also what support is there for them. What support do you need, and what's offered at M.D. Anderson.

So I'd like to introduce our first guest today and that's Barbara Englander. Barbara is 55. She lives in Metairie, Louisiana. And she has the love of her life, Sydney. And Sydney is a supervisor with the federal government's Consumer Product Safety Commission. And back 2005 Sydney got sick again. Earlier, years before, he had been treated for testicular cancer. He had had radiation, he had had treatment and there was always the concern, well, could he develop something else. Well, in 2005 he did. He developed an acute leukemia, AML, and there was Barbara by his side.

So, Barbara, welcome to the program. You feared that this would happen, and it did. You and Sydney decided to go five hours by car to go to M.D. Anderson, right?

Barbara:

Right. Yes, sir.

Andrew:

And I guess you're glad you did.

Barbara:

Oh, yes. They saved his life. They literally saved my husband's life. It's like I'm on a mission now that any time I hear anybody with any kind of leukemia or cancer it's just like I just want to take them and embrace them and tell them get up to M.D. Anderson.

Andrew:

Well, I do the same, and I went from Seattle to M.D. Anderson. But people do get good care at a number of centers. For you and me and Sydney it made a big difference, but you go from afar. And what we're going to talk with you, and happily Sydney is now two weeks after he got back from the treatment he had, and we'll describe that in a minute, he went back to work. And Sydney's doing pretty well these days, right?

Barbara:

Yes. He's doing good. He really is. He still doesn't have his full stamina back, but they said that would take a while. And he's working out and walking every day, so he's getting there. It's just a slower process, but he's been back to work, doing good.

Andrew:

But the process, as I like to say, from point A to point B, the journey is not always easy.

Barbara:

No, it's not.

Andrew:

Sydney had a bone marrow transplant and a matched unrelated donor. Wonderful woman named Terry from Palm Springs found out she was a match. M.D. Anderson found that match within two weeks, but it meant that you would be in a hospital room for weeks in a hotel by M.D. Anderson for months, and that's a tough road. And it was tough for you, wasn't it, Barbara?

Barbara:

Yes, it was. It was.

Andrew:

Was this one of the toughest things you ever went through in your life?

Barbara:

Yes, it is. I actually thought that when we first got into this that, Oh, it was a joke. Like, Oh, this is how it's going to be. I'm going to take care of you when you get older. But it's not. It's a lot harder. It's a whole lot harder.

FINDING SUPPORT AS A CAREGIVER

Andrew:

But when you go to M.D. Anderson and you don't know anybody and you're far from home, then you start seeing the pamphlets and the flyers by the elevators. You saw a flyer right off the bat. What did it say, and what action did you take?

Barbara:

There was a group saying it was "Caregivers: I've Got Feelings Too." And I knew that back in 2004 when he was originally diagnosed and put in the hospital for a month I didn't go get any kind of help. I figured I could just do it on my own. Well, you can't. You've got to have help, and the support group is the best thing that they have. It is so informative. I recommend it to everybody to go to the caregivers group.

Andrew:

So, Barbara, you saw this flyer, and then you called for the program, the support program and found out there was a support group once a week. You started going right off the bat?

Barbara:

Oh, yes. Right off the bat. Right off the bat.

Andrew:

And how did it feel going? I mean, if you go there, you don't know anybody. You're in a strange city. Did they make you feel welcome?

Barbara:

Oh, yes, very, very, very welcome. I mean they opened--they accept you with open arms. It's a group that you just bond, and you know that you're not alone, that there's other people that's going through similar or same things. And it's just the knowledge that you get from this. It's what you can take and use the rest of your life.

Andrew:

Now, did you find a buddy in the group, somebody else who is a caregiver?

Barbara:

Yes. I found a young girl named Amy, and the first day she came her and I hit it off and we were buddies all the way through the whole entire thing. We would take once a week. Like I explained to everybody when I went to the group, you have to learn to pick your times to when you can leave, because the most important thing is you have to take care of yourself, because if you don't take care of yourself you can't take care of your patient. And I can't stress that enough to people, that take care of yourself.

And you could pick your times when you leave your spouse or your loved one, when they've had their dinner, had their bath, and you'd let the nurses know that you were going to be leaving to go get some time for yourself. And they tell you to go. They strongly suggest that you go.

THE IMPORTANCE OF TIME TO YOURSELF

Andrew:

Well, you told me on the phone the other night that you also had your trips to was it Super Target?

Barbara:

Oh, Super Target was my home away from home there. That was just like the--that and Olive Garden. My girlfriend Amy and I would go once a week to Olive Garden and have our little lunch and just to talk and have our little time to ourselves. And, you know, we were there for each other. If you can hook up with the buddy, that's really, really good, because outside the group you still have support.

Andrew:

Well, Barbara, let's meet someone who helped you immensely, and that's a psychiatric advance practice nurse at M.D. Anderson Phyddy Tacchi. Phyddy, you've been involved in psychiatry for seven--18 years, actually, and seven years at M.D. Anderson, and you led the group that Barbara was in. What she was saying makes a lot of sense to me, and I imagine it's advice you give people, is you have to get support and take time for yourself because being a cancer caregiver is a big responsibility and it's a heavy load.

Ms. Tacchi:

Yes, that's true. I too have been a caregiver, and I learned through my experience how very frightening and lonely that role can be. And I after working here saw that there was a tremendous need for some sort of a process whereby caregivers could join together and experience just the universal need for support.

Andrew:

Well, tell me about what happens. She talked about going out to lunch, taking time for herself, saying that it was okay to leave the room. I know, Barbara you were actually sleeping in the same room with Sydney, both in the hospital for weeks and weeks and then in a hotel, right? So you were in one room.

Barbara:

Right. We were in the hospital five and a half weeks and I stayed there. We didn't have a hotel room. I stayed the entire time with him. And then we moved into the Rotary House, and we were there in one room with just two queen-sized beds and a little table and no living room for four and a half months. And then when Hurricane Katrina hit down here we didn't know what was going on with the house, so I told

Sydney, We need to go get an apartment because no telling how long we'll have to be here. And we moved into an apartment for another month and a half, and then we got released from the hospital and came home.

Andrew:

Wow. Now, you talked about some of the things you did.

Phydd, help us understand what you talk about in these support groups. How do they work? Are people venting, or are they offering suggestions? What are they doing there?

THE PURPOSE OF THE SUPPORT GROUP

Ms. Tacchi:

Sure. The purpose of our support group is to provide exactly that. It is to broaden the caregiver's horizons to looking at the person sitting next to them in the group who is going through similar trauma. The whole caregiving experience can be extremely traumatic, and to lessen that or to diminish that or to cushion that I don't think there's anything better than doing it in a group. I'm a group therapist by training, and our group is not just a support group but I would call it more of a psychoeducational type group in terms of the specifics of caregiving.

There is something magical or miraculous, I believe, that happens in a group. Because I'm of the strong belief that we are pack animals. We are meant to travel together, particularly during moments of crisis. And the cancer crisis can be quite a prolonged process, particularly in transplant patients where they need to stay in Houston for a lengthy time. I have many caregivers that have been here three to six to nine months and leaving all the familiarities and comforts of home behind.

So they travel to a strange city. They don't know the people. They don't know the streets. They don't understand oftentimes the language that we use in the medical setting. And one's life can change with one phone call. And then having to come to a very strange planet, it's an awesome experience.

INTERVENTION

Andrew:

One thing I'll mention is I did that, went to Houston. It was very strange and it was very far, and I'd never been to Houston before. The atmosphere at M.D. Anderson is tremendously warm and among patients and staff everybody down the hall, but still you're not necessarily making a personal connection with people. You're going to the doctor's appointments and the lab and maybe having procedures. So having a place to talk. So you have these support groups that meet. Now, also there are needs for couples.

Barbara, did Phyddy then meet with you and Sydney even in the hospital room?

Barbara:

Yes. She actually came one time when Sydney was having thoughts of--he wanted to hang himself. He was that depressed.

Andrew:

Oh, my.

Phyddy, let's talk about that. So there it sounds like I guess an intervention would really be needed. So you'll go right in the room and meet with the couple there and meet with them individually, I guess, too.

Barbara:

Yes. The process is that the patient's primary oncologist writes an order for me to come see the patient, and it's not unusual for me to come into the room during the highest point of the crisis. It's not unusual for patients to think about harming themselves or killing themselves simply to relieve themselves of the tremendous misery and suffering that they're having. I think having a third party come in and giving space for discussion regarding the depth of despair that the patient and caregiver are often feeling sometimes is very helpful.

Andrew:

I want to reinforce the point that Sydney is leading a good life now.

Barbara:

Oh, yes.

ILLNESS BRINGING YOU CLOSER

Andrew:

And your marriage, how would you characterize your marriage now having gone through all this, Barbara?

Barbara:

Oh, I explain it like a tube of Super Glue. That's how I put it. This illness has brought us so much closer, and we were already extremely close, but it's just amazing. I mean, my husband can look at me when we were up there and he would say, it's time for you - I would go home every six weeks, and we would have a relative go and stay with him for the weekend. Because he knew that it was extremely hard on me. And he would say, Look, you know, let's get your reservation made. You need to go get a break. I mean, he saw it. It was hurting him. As much as he was laying in that bed suffering, it was hurting him to see me go through it and watch him.

And it has brought us so much closer. I can't even explain it. It's like I said. It's like a tube of Super Glue. That's how we feel now.

Andrew:

Well, I think it's always terrific to think, to visualize, even, that people can get through this and be stronger for it and with the right treatment be healthier for it too.

We're going to take a short break. When we come back we're going to continue our discussion on the role that caregivers play and certainly what support is available to them, understand more of the benefits of it, of course, and what they can do for you if you come to M.D. Anderson and have the support of people like psychiatric advance practice nurse Phyddy Tacchi.

We'll be right back with more Patient Power sponsored by M.D. Anderson Cancer Center.

TAKING CARE OF YOURSELF

Andrew:

Welcome back to Patient Power as we continue our program on "Caregivers: A Vital Part of the Team" and what support is available to them. And we're visiting with Barbara Englander, who is from Metairie, Louisiana. She came over from there with her husband, Sydney, to M.D. Anderson in Houston where he had a transplant. She didn't know anybody over there. It was a strange, new experience for her and quite a journey for herself and Sydney over many months. They're doing great now, but she participated weekly in a support group led by psychiatric advance practice nurse Phyddy Tacchi.

Phyddy, let's continue our discussion. So we talked about helping people individually, going right into the hospital room, the weekly support group. What are things, though, that you counsel people to do for themselves? Barbara talked about having a buddy going out on a regular basis, having a chance to talk one-on-one with another caregiver. What other sorts of things, particularly when they're far from home?

Barbara:

Yes. I think one of the first steps is for a caregiver to realize, as Barbara mentioned, the need to take care of oneself. Caregivers often feel quite guilty in leaving the patient's bedside and going to do something pleasurable for themselves. I know as a caregiver I certainly did. And I learned through that experience how not to take care of yourself. So to give yourself permission to actually go out and experience something that takes you away from cancer, cancer, cancer.

I often explain it in terms of unplugging yourself from the patient and replugging yourself into something pleasurable so that one can recharge their batteries simply to fortify oneself so that they can start up the next day and do the same thing all over again.

COMMUNICATING WITH LOVED ONES

Andrew:

What are some things that people can do? So you have family members who are calling from afar. So let's say you go to Houston. You don't live around there. People are calling. What's going on, what's going on, what's going on. And maybe there are even people who say, You know, I could come over there and help too. So how do you counsel people so they can both disseminate information or have someone else do it and also draw on other resources?

Ms. Tacchi:

Yeah. Disseminating information about a patient's progress on a daily basis can often be extremely emotionally and physically draining for the caregiver. I often advise either they make up an e-mail distribution list and send out a report periodically to the various important people in their lives. Or, alternatively, if they're not internet savvy that they might leave a message on their answering machine at home giving updates perhaps on a daily basis or whenever they occur that people can call in to. Or that they assign a--let me think of the word--that they assign a main person who others can call for updates. So the name of the game is sparing oneself of emotional draining and to conserve and preserve whatever emotional and physical energy they have to take care of their patient.

But on a more practical bases I encourage caregivers to find distracting activities such as working puzzles, crossword puzzles, knitting, crocheting, walking, meditation, yoga, listening to music. However one can carve out even ten minutes of the day to get away from this is going to be a source of revitalization for them.

Andrew:

And what about if someone offers, let's say, to come over there? So somebody else from Metairie, where Barbara and Sydney are from, says, You know, I can come over there for a couple of days or a week to give you a break. A lot of people don't like to accept help. They say they want to be strong or they feel awkward about it. How do you advise people there?

Barbara:

Yeah. I think it's a fortunate situation, actually, where there is another warm body, so to speak, that is able to come in and relieve the caregiver. In relationships where that's a positive situation I often encourage caregivers to indulge, I guess is the right word, themselves in having someone else come in as a second line of defense.

There are some relationships, though, where that might not be the best same, and that, again, is a different scenario. And I counsel caregivers about how to discourage that person from coming.

Andrew:

Yeah, I was just going to ask you. So if you're at M.D. Anderson and, you know, nephew Frank says, Oh, I'll come over and help, and you're not sure Frank's the best player to come over, then maybe they could get some counsel from you on how to handle that.

Ms. Tacchi:

Absolutely, because that can be a delicate situation.

Andrew:

Okay.

Ms. Tacchi:

But oftentimes as the process continues and the caregiver becomes increasingly emotionally and physically fatigued, I think in more cases than not they do welcome having someone come in and providing some relief.

Andrew:

Oh, it's a wonderful blessing.

Let me ask Barbara. So, Barbara, people back in Metairie wanted to know what was going on. How did you do that medication or have it not be so taxing on you?

Barbara:

I used the internet and just hit my little mail list and it went out to everybody that it had to go to.

Andrew:

Wow. So you had like a little mailing list and you put out news reports.

Barbara:

Yes.

Andrew:

Were you ever relieved--did anybody ever come over and take your place or somebody else was with Sydney?

Barbara:

Oh, yes. I went home every six weeks, like clockwork.

Andrew:

Now, when you did that, who was with Sydney?

Barbara:

My brother went one time. His mother went one time. His brother went one time. And my sister went one time.

Andrew:

But it sounds like the bottom line for all this is you've got to take time for yourself.

And I'll just tell one personal story. It was not at M.D. Anderson, but my mother was in the later stages of advanced colon cancer in her 70s. My dad, trying to be a lawyer. He was still practicing. This was in south Florida, and I would come from afar and visit them. And I remember going to a lunch with my dad. I took him out to lunch because he just looked so fatigued. And I said, Dad, you are a patient too. You've got to see it that way. What are the prescriptions for you taking care of yourself? And he loved to play golf but he hadn't been. I said, Go play golf. You know Mom will want that.

Did Sydney have to sort of give you permission, Barbara? I knew you--I get the sense you're a pretty strong-willed lady, and you knew what you needed and you took that opportunity, but was Sydney supportive of all that?

LAUGHTER AS A NECESSITY

Barbara:

Oh, yes, very much. Very much. He knew that it was hard on me. And he would sit there and cry sometimes and say, I'm so sorry you have to see me go through this. And I'm like, Sydney, this is not something that you picked. I love you, and whatever it takes we're going to get through it. I was always very positive and very upbeat about it. You have to. We would laugh at the silliest little things. It got to the point where he was wearing a diaper. Well, we just thought it was so funny because I couldn't remember how to put a diaper on him. And when we did get it put on him we got a little bottle of champagne and we got the phone out and did a video for my daughter and my family back home because we were just laughing about.

Andrew:

What a great idea.

Barbara:

It's the silliest little things. You have to laugh, because if you don't have laughter in there the sorrow and the down part of it, it could just suck you in.

Andrew:

That sounds like great advice, Phydd. I'm sure you would endorse that.

Ms. Tacchi:

I absolutely would. And I think Barbara is such a wonderful role model for other caregivers about how to take this tragic situation and make it into something that provides growth and closeness and intimacy between people.

Andrew:

Rights, right. I always try when I've have had hard times to try and say, okay, this is a chapter in a book, but it's in the middle of the book, and I really believe the book is going to have a much more hopeful or upbeat ending, you know, like if you could visualize Sydney being cured, if you will, of his AML and going back to work and your marriage being strong.

Barbara:

Oh, yeah.

Andrew:

And I'm sure you had that dream, and now you're living it. So I think that's important.

Barbara:

Oh, yeah.

DEPRESSION AND FATIGUE

Andrew:

There was something mentioned earlier about deep depression of the patient, but also, Phyddy, I imagine that this can trigger depression in the caregiver. You're in the psychiatric field, so is it okay for the caregiver who may be down at M.D. Anderson to not just have talk therapy but to say, you know, Am I candidate for a medication to help me with what may be depression, have that discussion?

Ms. Tacchi:

Absolutely. That's a good point in that recent research studies show that caregivers are far more likely or vulnerable to depression and anxiety than the patient. Hard as that is to believe because the patient is certainly going through a rigorous time of their lives, but all of the medical eyes and attention are primarily focused on the patient, and the caregivers is objective left out into the periphery flailing about and trying to fend for themselves emotionally. It is not unusual for a caregiver to report symptoms of depression and anxiety. There are some caregivers who would be candidates for antidepressants and anti-anxiety medicines. And this is a time of life perhaps to look at the concept of better living through chemistry to get one's self through this.

One of the primary complaints of caregivers is fatigue, and that's due in large part to sleep deprivation. When people are sleep deprived the day begins to look gray, and one of the primary medications they may want to think about or ways to treat themselves is to grab sleep when they can.

Andrew:

Right. These are great points.

I want to mention that M.D. Anderson has a patient and caregiver telephone support line wherever you are and I want to give that number. 1-800-345-6324. 1-800-345-6324. And then in addition there are people like Phyddy Tacchi, psychiatric advance practice nurse, who have support groups and individualized service that can help. So make the call. Pick up the flyer.

Barbara, what would you say to people? There's somebody who may be listening to this even through one of those resource computers while they're at M.D. Anderson, or they may be coming down there. What would you say to them so that they get the help they need and underscore that it's available?

Barbara:

First of all, seek out a support group. Get the support from a support group because they're there. It's information that it's just like a book. You could just turn page after page and just get knowledge and support. That's what they're there for. You can't do this on your own. Physically, emotionally, you just can't do it.

Andrew:

You talked about the treatment, the transplant and the great gift that Terry gave your husband with the transplant material that saved his life. That was life saving for him. It sounds like, almost, as hard as this was that the support you got was life saving for you.

Barbara:

Oh, yes. Very much. Very much.

Ms. Tacchi:

Another source of information is a video that we made on caregiving that is available on the web on the M.D. Anderson website. And I believe it's under Patient Education. It's also on loan at the Family Resource Center, and it's in English and Spanish.

UTILIZING YOUR RESOURCES

Andrew:

Let's talk about those family resource centers. There are some of them spread around the M.D. Anderson campus, so that's a trigger point too. There are people you can go see, volunteers, many are cancer survivors or have been caregivers. And as Phyddy said she's been in that role herself. And then you can begin to draw upon the more formal service that are available.

Is there a charge for it, Phyddy? How does it work, like the support groups? How does that all that work?

Ms. Tacchi:

The support groups are free and they take place at the Place...*of wellness*, where all of their services are complementary. More formal psychiatric sessions, there is a charge, and most insurance companies will cover that.

Andrew:

I want to mention again your support group is called "Caregivers: I've Got Feelings Too," right, Phyddy?

Ms. Tacchi:

Exactly.

Andrew:

And it meets Thursdays noon to one at M.D. Anderson.

Ms. Tacchi:

And we serve lunch.

Andrew:

Oh, serve lunch, okay.

Barbara:

Really good lunches, too

Andrew:

And wonderful support, one-to-one and as a group. I'm going to give the phone number as well. It's a Houston phone number, 713-794-4700. 713-794-4700. And you can preregister.

How many people are typically in the support group, Phyddy?

Ms. Tacchi:

We take a maximum of nine, and I am number ten. I believe that a group larger than that is not as therapeutic. I do want to mention the name of the video, though.

Andrew:

Oh, please.

Ms. Tacchi:

When one goes to the Patient Resource Center or goes online to look for the caregivers video the title is "Caring For the Cancer Patient: The Caregiver's Perspective." And we are also going to have a video available by the end of the year interviewing couples and the impact of cancer upon their marriage, and Barbara and Sydney will be a part of that.

Andrew:

Oh, terrific. And I'm sure if you go to any of these resource centers around M.D. Anderson they'll know about that video, and you can just ask.

So, again, we've been visiting with Phyddi Tacchi, who is a psychiatric advance practice nurse. She has that support group once a week, "Caregivers: I've Got Feelings Too." It made a huge difference for Barbara. And then of course we have the love story, I think, of Barbara Englander and Sydney who came from Metairie, Louisiana, went through months and months and months of care and Barbara getting support and taking breaks and laughing, the whole story--she's told you the highs and the lows--and now are leading a full life.

Barbara, I wish you and Sydney all the best. I want that love story to go on for many years.

Barbara:

Oh, it will, believe me.

Andrew:

Yeah, I know. It's a terrific story.

And, Phyddi Tacchi, all the best to you and your very critical work in your supporting caregivers.

Ms. Tacchi:

Thank you.

Andrew:

This has been another edition of Patient Power. We're here every two weeks with a new program, and of course all our replays are on the mdanderson.org website. It's mdanderson.org/patientpower.



Thanks for being with us. Thanks to all our guests. I'm Andrew Schorr. You've been listening to Patient Power brought to you by M.D. Anderson Cancer Center.

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